

## Développement Humain, Handicap et Changement Social Human Development, Disability, and Social Change



# Involving Disabled People in HIV and AIDS Risk Reduction Programmes in Binga District, Zimbabwe

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Volume 19, numéro 2, octobre 2011

De l'appropriation du pouvoir et de l'autodétermination : le parcours  
du mouvement social des personnes ayant des incapacités  
Empowerment and Self-Determination of People with Disabilities:  
History of a New Social Movement

URI : <https://id.erudit.org/iderudit/1086901ar>

DOI : <https://doi.org/10.7202/1086901ar>

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Éditeur(s)

Réseau International sur le Processus de Production du Handicap

ISSN

1499-5549 (imprimé)

2562-6574 (numérique)

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Citer cet article

Munsaka, E. (2011). Involving Disabled People in HIV and AIDS Risk Reduction Programmes in Binga District, Zimbabwe. *Développement Humain, Handicap et Changement Social / Human Development, Disability, and Social Change*, 19(2), 69–80. <https://doi.org/10.7202/1086901ar>

Résumé de l'article

Le mot « désastre » fait aujourd'hui partie de notre vocabulaire de tous les jours. L'attention actuellement portée sur les inondations, les famines, les tsunamis et les tremblements de terre a eu toutefois pour effet de réduire celle témoignée aux effets dévastateurs d'un autre « désastre », la pandémie de VIH/SIDA. L'accroissement de l'attention portée à la survenue des catastrophes naturelles a eu pour incidence le développement de l'intérêt à comprendre la nature des risques et les vulnérabilités vécues par les personnes y étant confrontées. Le paradigme de la gestion des risques de catastrophes repose sur le concept de réduction des risques et valorise la participation des personnes à risque dans les prises de décision.

Cet article présente les résultats d'une étude empirique à petite échelle conçue pour explorer le niveau de participation des personnes ayant des incapacités dans les programmes de prévention des risques associés au VIH/SIDA dans le district de Binga, au Zimbabwe. Il expose l'exclusion systématique de ces personnes dans la gestion de ces programmes. L'article soutient que les personnes sourdes, ainsi que celles ayant des difficultés d'apprentissage et les femmes ayant des incapacités sont particulièrement vulnérables face à une telle exclusion des programmes de prévention des risques.

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## Involving Disabled People in HIV and AIDS Risk Reduction Programmes in Binga District, Zimbabwe

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Article original • Original Article

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### Abstract

The term "disaster" now forms part of our everyday vocabulary. Current attention focused on floods, famines, tsunamis and earthquakes has, arguably, undermined attention on the devastating effects of another "disaster", the HIV/AIDS pandemic. Increased attention to disaster occurrences across the globe has injected greater interest in understanding the nature of risks posed and vulnerabilities experienced in the face of a range of "disasters". An emphasis on risk reduction occupies the core of the disaster management paradigm that values the participation of those "at risk".

This article presents the findings of a small scale empirical study designed to explore the involvement of disabled people in HIV/AIDS risk reduction programmes in Binga District, Zimbabwe. It exposes the systematic exclusion of disabled people from such programmes, and argues that deaf people, those with learning difficulties and disabled women appear to be particularly vulnerable to exclusion from such programmes.

**Keywords :** HIV/AIDS, disabled people, deaf, risk prevention programme, disaster management

### Résumé

Le mot « désastre » fait aujourd'hui partie de notre vocabulaire de tous les jours. L'attention actuellement portée sur les inondations, les famines, les tsunamis et les tremblements de terre a eu toutefois pour effet de réduire celle témoignée aux effets dévastateurs d'un autre « désastre », la pandémie de VIH/SIDA. L'accroissement de l'attention portée à la survenue des catastrophes naturelles a eu pour incidence le développement de l'intérêt à comprendre la nature des risques et les vulnérabilités vécues par les personnes y étant confrontées. Le paradigme de la gestion des risques de catastrophes repose sur le concept de réduction des risques et valorise la participation des personnes à risque dans les prises de décision.

Cet article présente les résultats d'une étude empirique à petite échelle conçue pour explorer le niveau de participation des personnes ayant des incapacités dans les programmes de prévention des risques associés au VIH/SIDA dans le district de Binga, au Zimbabwe. Il expose l'exclusion systématique de ces personnes dans la gestion de ces programmes. L'article soutient que les personnes sourdes, ainsi que celles ayant des difficultés d'apprentissage et les femmes ayant des incapacités sont particulièrement vulnérables face à une telle exclusion des programmes de prévention des risques.

**Mots-clés :** VIH/SIDA, personnes handicapées, sourds, programme de prévention, gestion des risques de catastrophes

## **Introduction and Background**

**T**here has been an increase in disaster occurrences witnessed over the last decade with 2004 and 2005 having recorded the worst disasters in living memory (DFID, 2006). The focus on one-off-events such as earthquakes and floods has distracted attention from the devastating effects of the HIV/AIDS disaster but has also injected greater interest in understanding the risks and vulnerability experienced by people exposed to disasters largely as a result of human action (or inaction) and behaviour (UNDP, 2004).

Disasters are understood both as the result of geological, climatic or biological triggers and the result of social politics and economic environments (Wisner et. al, 2004). Rodriguez, Quarantelli, and Dynes (2007) have argued that a disaster can be distinguished by its serious disruption to the functioning of society, causing widespread human, material or environmental losses which exceed the ability of the affected society to cope using its own resources. Degrees of vulnerability to a disaster event vary widely reflecting the socio-economic and political environments of those who are affected, resulting in different groups of people being affected differently by a disaster. This article draws on a study of a single district in Zimbabwe focussing on the impact of the HIV/AIDS pandemic on disabled people.

In April 2004, the World Bank and Yale University published a report "HIV/AIDS and Disability: Capturing Hidden Voices", summarising the results of a global survey on HIV/AIDS and disability (Janssen, 2005). This survey showed that disabled people are at equal or increased risk of exposure to all known risk factors for HIV including poverty and marginalisation (Janssen, 2005). Various sources (Van Biema, 1994; Collins et al, 2001; Groce, 2003; Mulindwa, 2003 in Groce, 2004; UNIRIC, 2004; Hazangwi, 2004) document illuminating evidence of disabled people's HIV risks. Governments around the world have come up with comprehensive packages in response to the HIV/AIDS pandemic. In the case of Zimbabwe, a national

AIDS policy (Ministry of Health and Child Welfare, 1999) was introduced in response to the socio-economic impact of HIV/AIDS. This policy underpins large scale programmes in HIV/AIDS prevention, care and mitigation undertaken by a range of government and non-government stakeholders. Furthermore, The Disabled Persons Act Chapter 17:01 Revised Edition (Government of Zimbabwe, 1996) outlawed any form of discrimination against disabled people. Notwithstanding this evidence, it is argued here that there has been little acknowledgement by policy makers, implementers and major actors in the field of HIV/AIDS that specific efforts are required to ensure that disabled people, with distinctive issues and specific needs, are equally included in risk and harm reduction programmes in Binga district, Zimbabwe. In fact, there is little evidence that programmes designed to address the risks and vulnerabilities arising from HIV/AIDS have paid attention to the needs of disabled people.

## **The Participation or Involvement of Disabled People in HIV Risk Reduction**

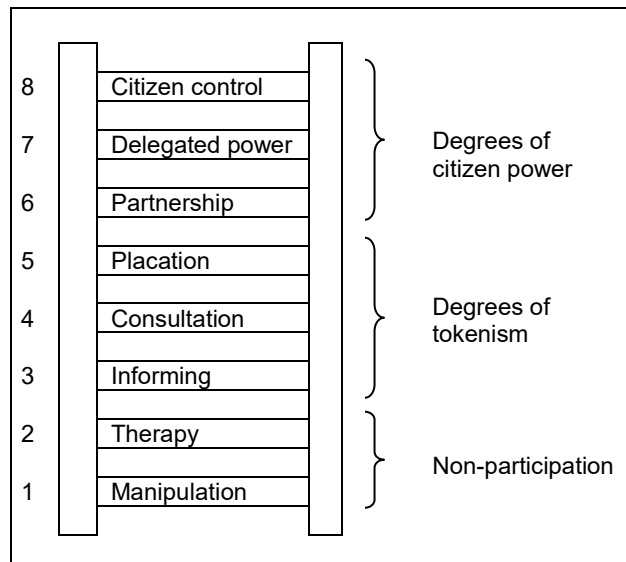
The concept of participation is widely used in the discourse of development. In fact, it is central to some of the fundamental questions that have plagued the force and reach of development theory. It is not unfamiliar therefore to come across terms like "community participation", "empowerment" and "citizen participation" throughout the literature. The terms participation and involvement feature frequently in this discussion and are used interchangeably. Participation, according to Gaventa (2002 : 1) implies pathways through which poor people exercise voice through "new forms of deliberation, consultation and or mobilisation designed to inform and to influence larger institutions and policies." Disabled people have long been recognised as constituting the poorest group in any given community (Yeo, 2001). However, disabled people's participation in HIV/AIDS risk reduction programmes should not be perceived solely in terms of the survival of disabled people in the face of the disaster, but also as an important means by which disabled people can fulfil the obligations of active citizenship taken for granted by non disabled people.



In the context of disaster risk reduction, the participation of disadvantaged groups including disabled people has gained recognition in recent years. As Devlieger (1999) explains, the declaration of The International Year of Disabled Persons in 1981 by United Nations not only spurred interest in disability, but also marked the official beginning of the recognition of the rights of disabled people in development work. The World Programme of Action Concerning Disabled Persons (United Nations, 1983) called for particular efforts to be made by governments to integrate disabled people in the development processes, to improve prevention and rehabilitation programmes, and to equalise opportunities for the participation of disabled people. This Programme of Action marked the beginning of the United Nations (UN) Decade of Disabled Persons (1983-1992), which culminated in the adoption of the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities in 1993. Although not a legally binding instrument, the Standard Rules set an anti-discriminatory, inclusive, international standard and represented a strong moral and political message to governments and organisations to take action to attain equalization of opportunities for disabled people (UN, 1993; Yeo, 2005). And since then, there has, arguably, been increasing reference to disability as an international development issue. Thus, involving disabled people in HIV risk reduction programmes is consistent with the principles of participatory development.

Asserting that citizen participation is citizen power, Arnstein (1969) depicted participation as an eight-rung ladder, with each rung corresponding to the extent of citizens' decision-making responsibility or power in determining a desired outcome as shown in the diagram below.

### ARNSTEIN'S LADDER OF PARTICIPATION (1969 : 217)



Arnstein's point of departure is citizens on the receiving end of projects or programmes (Cornwall, 2008; Bowen, 2008). The lowest rungs of the ladder represent activities that parade as participation, but involving little or no choice for participants does not really constitute participation. Activities associated with "tokenism" are widely visible in the efforts of most development organisations claiming to promote participation (e.g. consultation, giving information). Consultation is arguably the lower end of user involvement as its focus is on less than full participation in decisions about services (Barnes, 1999). However, consultation is widely used as a means of legitimating decisions already-taken by staff of most non-government organisations (Cornwall, 2008) while at the same time maintaining "top down" control of decision-making processes (Lane, 2005, p. 183). It provides a thin veneer of participation to lend the process moral authority. In contrast ***genuine participation involves the exercise of power by citizens including*** [emphasis added] disabled people who may be the target beneficiaries of programmes.

Participation of populations in tackling their own problems has proved to have significant advantages. Both the Zimbabwe Lawyers of Human Rights (2006) and Landsdown (1995 cited in Mayo 2001) argue that participation not

only gives political legitimacy to decision-making, but is also a democratic right. Further, drawing on local community-based knowledge and expertise, participation builds ownership of decisions and trust as well as consensus and shared vision for the future. In this context therefore, participation is not only based on ethical and moral grounds but is also a pragmatic instrument for the empowerment of marginalised people, including those who are disabled. This view bonds well with the principles of the sustainable development paradigm.

The involvement of disabled people in issues that affect them was a factor in the foundation of the Jairos Jiri movement in Zimbabwe in 1945 (Devlieger, 1995). Started as a personal initiative to help disabled Africans, it became part of a larger self-help movement in colonial Rhodesia, now Zimbabwe. The idea that disabled people were able to work for themselves, and to lead a life as respectable and useful as that led by non-disabled people elsewhere (Devlieger, 1995, p. 45), was central to Jairos Jiri's philosophy. Although the concept of "self-help" as used by Jairos Jiri conveys a sense of self-provisioning, it is also about meaningful participation, usually necessitated by the individual's awareness and knowledge about the subject of concern. As Burns, Williams and Windebank have argued, "self-help is critical to building the moral fabric of society" (2004, p. 16). This philosophy (self-help) was cemented by the government of Zimbabwe through the introduction of disability legislation (Pembrey, 2006; Chitiyo & Wheeler, 2004). But despite these promising foundations, disabled people remain conspicuous by their absence in discourses on HIV/AIDS in Zimbabwe.

### **The Binga Study**

This section describes, and presents the findings of, a small scale qualitative study carried out in 2007 in Binga District, Zimbabwe. The objectives of the study were :

- to explore disabled peoples' perceptions of HIV/AIDS and the impact of the HIV/AIDS pandemic;

- to determine the extent to which disabled people who are adults were involved in HIV/AIDS intervention programmes;
- to discover whether AIDS programmes outreach activities were reaching disabled people, either as members of the general population or through targeted efforts.

Three key programmes : HIV/AIDS Awareness (Advocacy), Home Based Care, and a Nutrition and Supplementary Feeding Programme, all designed to avert, reduce or respond to the threats posed by HIV/AIDS were the focus for an exploration of the involvement of disabled people.

The choice of Binga District was informed by its history as a marginalised district within Zimbabwe and by the author's detailed knowledge of the area and the Tonga language. Located in Matabeleland North province, Binga is both geographically remote and very poor, ranking 75th of 77 districts of Zimbabwe in the Human Development Index in 2000 (Save the Children Fund-UK (SCF), 2002) and having the highest Human Poverty Index in the country. Very high levels of deprivation and illiteracy (SCF, 2002; 2004) have led to the influx and involvement of non-government organisations (NGOs) as major players in implementing development programmes and HIV/AIDS risk reduction programmes. While poverty and disability are inextricably linked (Elwan, 1999), forming a cycle of cumulative causation, HIV/AIDS thrives on poverty (Yeo, 2005) and disabled people are over-represented in this category (Katsui, 2007). Thus, exploring the extent to which disabled people in a district with very high levels of deprivation (Manyena, 2006) are involved in HIV risk reduction initiatives becomes not only necessary but imperative in view of these interconnections and the prevalence of HIV infection in Zimbabwe.

Of Zimbabwe's estimated population of 12.8 million (Central Statistical Office (CSO), 2002), 10-12% are estimated to be disabled (Mont, 2007). The prevalence of HIV infection was reported at 33.7 % in 2002 but by 2006 had fallen to 20.1% (UNAIDS, 2007). Hazangwi (2004) estimated that about 300,000 (approx-



mately 25%) of disabled adults were living with HIV in 2003. In Binga, with a population estimated at 118,824, in 2002) (CSO, 2002) we might expect about 12000 people to be disabled. At the time of conducting this study, in 2007, registers of rehabilitation clients and those who were registered as beneficiaries under the national disability allowance totalled 843. Assuming that around 40% of the population is under fifteen, this suggests that health and welfare services are aware of the great majority of disabled adults in Binga District, although it is possible that there is some duplication of individuals across these two services, a situation that would imply knowledge of a lower proportion of the disabled adult population. One safe conclusion we can draw is that there are at least several hundred disabled adults in Binga District.

### Research Participants

Study participants included forty disabled men and disabled women, ten family members, committee members of six Village AIDS Action Committees, four disabled people's organisations, two key government departments and three non-government organisations, one national and two international non-governmental organisations. A quota sample of disabled men and disabled women, distributed evenly between those experiencing physical disability, visual impairment/blindness, deafness and learning disabilities, was selected from disability registers and disability allowance registers which were obtained from the local district hospital and local social welfare office respectively. Family members were identified using snowballing techniques, while Village AIDS action committees (VAACs), disabled people's organisations, government departments, District AIDS Action Committee (DAAC) and Ministry of Health and Child Welfare (MOHCW) and non-government organisations were selected purposively on the basis of their relevance to the study. The study was subject to ethical approval with all participants giving informed consent to participate, being guaranteed anonymity and having the right to withdraw from the research at any stage.

No claims for representativeness (Sarantakos, 1998, p. 141) can be made on the basis of this small sample. However, the diversity of the sample of disabled people, family members, and representatives of disabled people's organisation, government and non-government organisations provides an opportunity to explore a range of views and experiences of different disabled people in relation to their involvement in HIV/AIDS risk reduction programmes.

### Methods

Semi-structured interviews with twenty disabled women and twenty disabled men covered knowledge and awareness of HIV/AIDS prevention and amelioration programmes. One focus was on finding out if disabled people were aware of, and able to access free supplies of condoms. I also sought to establish whether disabled people were informed of the testing and counselling services that were available in their localities, and if they had taken, or would take advantage of HIV testing as well as their views on the service. And finally I focused on whether they were involved in one or more of three programmes in the district designed to prevent or ameliorate the effects of HIV/AIDS : (HIV/AIDS Awareness, Home Based Care and Nutrition and Supplementary Feeding). Semi-structured interviews with directors or senior officers of NGOs permitted an insight into these programmes, the level of involvement of disabled people, and the benefits and limitations of the programmes in serving the population of disabled people of Binga District. Semi-structured interviews were also conducted with representatives of four organisations of disabled people, the Ministry of Health and Child Welfare and the District AIDS Action representative. Interviews with family members served to validate information from disabled participants. Focus group discussions (FGDs) were conducted with 32 men and 29 women members of the six Village AIDS Action Committees (VAACs) with each focus group including 9-11 participants invited through their respective chairpersons, who were also ward councillors. Individual participants and focus group members chose where and when dis-

cussions were to be held. Each interview participant was given a written or verbal account of the information they had shared in order to check the accuracy of their accounts. This was particularly important since the participants were unwilling to be tape recorded.

## Findings

In this section I present the findings of the research study based on the three programmes covered by the study : HIV/AIDS Awareness (Advocacy), Home Based Care, and Nutrition and Supplementary Feeding. These national programmes were initiated by the government of Zimbabwe through the Ministry of Health and Child Welfare as part of the national response to the HIV/AIDS pandemic and supported by both national and international non-government organisations. The findings are presented to illuminate nuanced differences of involvement among and between the different groups of disabled people.

### HIV/AIDS Awareness (Advocacy) Programme

Exploring issues of awareness and involvement in individual interviews revealed two clear messages. First, despite the fact that many

disabled people in the district had their own children, they were conveniently constructed by non-disabled people as being sexually inactive. As "Lee", a woman who uses a wheelchair to move around explained : "*Ibantu batalimene babonanga iswe tulimele teenga tulabujata pe bulwazi bwa-AIDS.*" ["Those non-disabled people think we can not contract HIV/AIDS"]. This construction left disabled people largely outside the remit of the HIV awareness programme which involved HIV testing and counselling services as well as access to condoms. None of the participants who participated in the study participants knew their HIV status. The effective exclusion of disabled people serves to perpetuate the misconception that HIV is only spread through unprotected sexual intercourse with anyone who has the virus. Yet, sexual intercourse is only but one way through which the virus is spread between human beings (Collins, 2009). Second, despite government efforts in raising awareness about HIV/AIDS related issues, disabled participants were largely unaware of the HIV/AIDS advocacy programmes in their area. Table 1 summarises disabled people's awareness of and involvement in the HIV/AIDS awareness programme.

**TABLE 1 : PARTICIPATION OF DISABLED PEOPLE IN THE HIV/AIDS AWARENESS PROGRAMME**

| Disability Grouping     | Number of Interviewees |           | Aware and Involved |          | Aware but not Involved |          | Total     |
|-------------------------|------------------------|-----------|--------------------|----------|------------------------|----------|-----------|
|                         | M                      | F         | M                  | F        | M                      | F        |           |
| Physical Disability     | 5                      | 5         | 1                  | 0        | 2                      | 3        | 6         |
| Visual Impairment/Blind | 5                      | 5         | 0                  | 0        | 0                      | 2        | 2         |
| Learning Disability     | 5                      | 5         | 0                  | 0        | 2                      | 0        | 2         |
| Hearing Impairment/Deaf | 5                      | 5         | 0                  | 0        | 1                      | 0        | 1         |
| <b>Total</b>            | <b>20</b>              | <b>20</b> | <b>1</b>           | <b>0</b> | <b>5</b>               | <b>5</b> | <b>11</b> |



Of the forty disabled people who took part in the study, only one physically disabled man was both aware of, and involved in, the HIV/AIDS Advocacy programme. Although a further three physically disabled women, two physically disabled men, two blind women, two learning disabled men and one deaf man knew of the programme in this social context in which disabled people are not perceived in terms of sexual identity, they were effectively excluded from it. Table 1 also shows interesting variation in knowledge between disabled men and women and between differently disabled people. In particular men and women who are blind, deaf or learning disabled appear to be much less likely to be aware of HIV/AIDS awareness initiatives. However, caution must be exercised in interpreting these findings since the numbers are too small to demonstrate any statistical significance.

### Nutrition and Supplementary Feeding Programme

The Nutrition and Supplementary Feeding Programme is one intervention to support those affected by HIV/AIDS. HIV/AIDS and nutrition are intimately linked. Poor nutrition can damage the immune system and contribute to the

acceleration of full-blown AIDS, while AIDS itself may lead to malnutrition (Food and Agricultural Organisation (FAO), 2003). Piwoz and Preble (2000) also assert that maternal malnutrition increases mother-to-child transmission. They also state that HIV positive people require 50% more protein and 15% more calories in order to remain healthy and require between two and five times as much of key vitamins and minerals to strengthen their immunity. Gillespie, Haddad and Jackson (2001) also acknowledge the importance of nutritional care and support of individuals with HIV positive status. Appropriate nutritional care and support is critically important in preventing or forestalling nutritional depletion for individuals living with HIV/AIDS. Thus, the Nutrition and Supplementary Feeding Programme is a crucial component in responding to HIV/AIDS at district level. Yet, only two visually impaired women, of the sample of forty disabled people were aware that the Nutrition and Supplementary Feeding Programme was being implemented in their localities. Furthermore, not a single disabled participant was included in any component of this programme. Table 2 below summarises disabled people's awareness of and involvement in the Nutrition and Supplementary Feeding Programme.

**TABLE 2 : PARTICIPATION OF DISABLED PEOPLE IN NUTRITION AND SUPPLEMENTARY FEEDING PROGRAMME**

| Disability Grouping     | Number of Interviewees |           | Aware and Involved |          | Aware but not Involved |          | Total    |
|-------------------------|------------------------|-----------|--------------------|----------|------------------------|----------|----------|
|                         | M                      | F         | M                  | F        | M                      | F        |          |
| Physical Disability     | 5                      | 5         | 0                  | 0        | 0                      | 0        | 0        |
| Visual Impairment       | 5                      | 5         | 0                  | 0        | 0                      | 2        | 2        |
| Learning Disability     | 5                      | 5         | 0                  | 0        | 0                      | 0        | 0        |
| Hearing Impairment/Deaf | 5                      | 5         | 0                  | 0        | 0                      | 0        | 0        |
| <b>Total</b>            | <b>20</b>              | <b>20</b> | <b>0</b>           | <b>0</b> | <b>0</b>               | <b>2</b> | <b>2</b> |



The Nutrition and Supplementary Feeding Programme consisted of three components : food distribution, setting up nutrition gardens and food preparation. Non-government organisations responsible for food distribution worked with community leaders to hire additional temporary staff to support food distribution. Disabled people, however, were not considered. A female participant, "Ju" said : *"Aswebo kulin-da tula kozya, kubala mazina tulakonzya. Asi manje iswe dowakusika alya afozigwa zilyo, ulamvwa anyinywe nimutaboni muyandanzi awa. Eyimilimu iyanada ibabona,* "[we can guard the food. I can read the names of beneficiaries. But when I go at the food distribution point, I'm turned away. I'm told this job is for non disabled people].

The second component involved setting up nutrition gardens in villages. Members of the six Village AIDS Action Committees who took part in this study received support and advice from NGOs on running and managing the nutrition gardens, provision of seeds, fencing material and well digging. Money generated through selling the produce from the nutrition gardens, was used to sustain the committees' activities and for their own consumption. But part of the produce was given to individuals identified as HIV positive. Disabled people were conspicuous by their absence from membership of Village AIDS Action Committees. And because their HIV/AIDS status was unknown, the result of exclusion from testing programmes, they were also denied access to garden produce. Here we see one exclusionary process compounded by another, preventing disabled people from contributing to, and benefitting from, the nutrition gardens.

The third component of this programme focussed on food preparation and food hygiene. Trainers or facilitators in food hygiene were provided by the sponsoring NGOs. However, despite the importance of this programme in fighting the effects of HIV, disabled people were again conspicuous by their absence. To summarise, disabled people's exclusion from the Nutrition and Supplementary Feeding Programme demonstrates the cumulative impact of non-recognition (Fanon, 1986), and ensure processes that deny disabled people access both to the rights and responsibilities of citizenship.

### Home Based Care Programme

Home Based Care is one model of health care delivery to support people living with HIV/AIDS (Natasha, Musau, & Chanfreau, 2005). The World Health Organization (WHO) defines this as the provision of services in support of the HIV/AIDS care process that take place in the home of the HIV-infected person (WHO, 1989). Home Based Care includes physical, psycho-social, palliative, and spiritual activities (WHO, 2002) including clinical care, providing personal care and oral hygiene, care for clothes, cleaning the house, food preparation, fetching water and paying attention to toilet needs, and comfort as well as providing up-to-date, accurate information on HIV/AIDS. These are everyday tasks that people undertake in their homes and houses. Table 3 below shows the awareness and involvement of disabled people in the Home Based Care Programme.

**TABLE 3 : PARTICIPATION IN HOME BASED CARE PROGRAMME**

| Disability Grouping     | Number of Interviewees |           | Aware and Involved |          | Aware but not Involved |          | Total    |
|-------------------------|------------------------|-----------|--------------------|----------|------------------------|----------|----------|
|                         | M                      | F         | M                  | F        | M                      | F        |          |
| Physical Disability     | 5                      | 5         | 0                  | 0        | 2                      | 1        | 3        |
| Visual Impairment/Blind | 5                      | 5         | 0                  | 0        | 3                      | 1        | 4        |
| Learning Disability     | 5                      | 5         | 0                  | 0        | 1                      | 0        | 1        |
| Hearing Impairment/Deaf | 5                      | 5         | 0                  | 0        | 0                      | 0        | 0        |
| <b>Total</b>            | <b>20</b>              | <b>20</b> | <b>0</b>           | <b>0</b> | <b>6</b>               | <b>2</b> | <b>8</b> |



Only six men and two women of the sample of forty disabled people were aware of the Home Based Care Programme in their communities. This apparent lack of awareness on the part of the women seems particularly worrying in the light of evidence that women are biologically, socio-economically, and socio-culturally more at risk of HIV infection than men (Topouzis, 2000). The central role of female relatives in caring for HIV infected individuals (Zimbabwe Women's Resource Centre and Network, 2003) adds to the paradox. None of the eight participants who were aware of the Home Based Care Programme were involved in it, despite evidence of disabled people's engagement in caring tasks including personal care, preparing meals, fetching water (women), building shelters (men) and shopping (women and men) in their homes. The implication is that disabled people's capacity for caring within the family remained unseen or unacknowledged by the local village leadership who nominated volunteers for inclusion in programme activities. This lack of acknowledgement was exacerbated by the unquestioning acceptance by programme managers of the nominations from the village leadership that was dominated by men.

The message from each of these three programmes is that disabled men and women are consistently overlooked both as potential contributors to, and beneficiaries of, HIV/AIDS awareness and amelioration programmes and evidently not treated as valued members of society. Almost half of the sample of disabled people was unaware of programmes in their communities. Deaf participants were the least likely to be aware, followed by those who were learning disabled. And overall, disabled women were less likely to be aware of programmes than men. It must be stressed, however, that no statistical significance can be attached to these differences.

### Organisational Perspectives

The stark message conveyed from the previous sections is that the involvement of disabled people in the three programmes (HIV/AIDS Awareness, Nutrition and Supplementary Feeding and Home Based Care Programmes)

is conspicuous by its absence. The director of one participating NGO said, "...disabled people are not involved in our programmes." And the director of another NGO said; "Of the forty seven volunteers my organisation trained, none has a disability", confirming the depth of exclusionary practices by implementing organisations. Justifying such absence from district wide programmes has never been easy or straightforward. "Yo", a blind woman, explained: "*Nsiziye kuti ime balekelanzi kundisaluzya kuti ndibe umwi wabo.*" [I don't know why they don't choose me to be part of the group.] And Zye, a blind man, said "*Batulangila ansi ! Bantu batayiide tabaswilizigwi pe... bayiingi besu tatinkide pe kuchikolo.*" [The non-disabled people look down upon us. The uneducated ones are not listened to, and many of us never went to school]. Referring to possible causes of exclusion the director of an NGO identified problems in the selection process and explained: "I think we have to rethink our process by which we choose our participants...we have put too much trust into the hands of the community leaders... that could be the cause of the omission... but what can we do? We want local communities to own the programmes..." This response helps to demonstrate the complexities faced by NGOs in implementing what they perceive to be participatory programmes. The objective to achieve local ownership of their programmes for sustainability reasons, consciously or unconsciously forced programme implementers to seek and accept without question, nominations from local leadership. The local leadership at village and ward level as spelt out in The Traditional Leaders Act of 1999 (Masendeke, Mlala, Ndlovu, & Gumbo, 2004) comprises of the local chief, councillor and village heads who are empowered to co-ordinate development. They have the responsibility for identifying the beneficiaries and participants of programmes in their localities.

As Cornwell (2008, p. 271) has argued: "the motivations of those who adopt and practise participatory approaches is an important factor" in shaping interventions as well as determining who is included. And the success of any programme is heavily dependent on the imple-

menting organisation's working relationship with local leadership structures. Citizen participation is bound up with issues regarding power, privilege and resources (Bowen, 2008). Those with the resources, power and knowledge to shape definitions of rights, citizenship and how they are put into practice are usually more able to turn rights discourses and entitlements to their advantage. But to lay the blame entirely on the traditional leadership for the exclusion of disabled people would be ignoring the responsibility any government has to its citizens in ensuring their meaningful participation, a process that involves political will to convert professed commitment to citizen participation into tangible actions (Gaventa & Robinson, 1998). In the context of Zimbabwe the lack of a national disability policy provided a convenient excuse for programme planners and service providers to exclude disabled people from the programmes. Writing about Zimbabwe, Dube and Charowa (2005) have noted that disability issues are not mainstreamed into each and every sector. Rather, disability issues are perceived as areas to be dealt with by disability experts (education, employment, culture, media etc). The result, expressed by the NCDZ representative who took part in this study is that "disabled people do not have an adequate and legally binding tool to demand inclusion in all these programmes."

## **Conclusion**

This critical analysis of the involvement of disabled people in HIV intervention programmes is based on data collected in interviews with disabled people, community leaders and NGO representatives in Binga District, Zimbabwe. With no independent funding, the study was limited in scope. However, while no generalisations can be made on the basis of the findings the study of small groups or individuals sharing certain characteristics is typical of qualitative research where generalisability is less important (Gray, 2004). As Bryman (2001, p. 272) writes, it is "depth" or 'thick descriptions' rather than the "breath" that is a preoccupation in qualitative research. It is also important to bear in mind the cultural context in which the study was undertaken and the chal-

lenges of conveying the meaning of concepts and emotions expressed in Tonga, some of which have no direct translation to English. Within these limitations I argue that, despite some national effort and progress in the fight against HIV/AIDS, disabled people in Binga have been excluded from opportunities for positive action in responding to the HIV/AIDS epidemic. A number of factors appear to be involved in this systematic exclusion. Disabled people have been conveniently constructed as "asexual", therefore immune from HIV infection and AIDS and so inappropriate candidates for inclusion in HIV/AIDS awareness programmes. They have also been conveniently constructed as "unable" rather than "disabled", and so unlikely contributors to community based programmes to prevent or ameliorate the effects of HIV/AIDS. So despite Zimbabwe having developed some policies to tackle discrimination against disabled people, these have not been effectively mainstreamed to reach HIV/AIDS risk reduction practices. Consequently disabled people in Binga District remain significantly exposed to HIV risks. Further studies with larger samples could help to determine how best disabled people could be mainstreamed in HIV/AIDS risk reduction programmes in Binga District and more widely. But perhaps more urgent is the need to adopt specific strategies to secure the participation of disabled people in the fight against HIV/AIDS. Policies for HIV/AIDS prevention and amelioration are well established but more vigorous translation of the policy to practical activities at all levels of communities is required to ensure that all sections of the community, including disabled people, are enabled to participate in, and benefit from them.

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